

Multiple Disabilities: Parental Perspective

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Abstract- The study aimed to discover answers pertaining to process of intervention and perception based upon a 36 item questionnaire put forth to 40 parents having children with multiple disabilities. Children were in the mean of 9.9 years and attended NIEPMD for 2.18 years; most frequent (48%) associated conditions were Cerebral Palsy along with mental retardation. The mean age of suspicion by parents was at 24.2 months followed by doctor visit by 27.2 months and initiation of rehabilitation by 56.14 months. The core concern for 80% parents was to develop motor and speech skills, although the majority (55%) had neglected speech therapy. Clients preferred a transdisciplinary approach (68%) over the present multidisciplinary approach. Acceptance of the child's condition is a crucial, 56% parents took an average of 8.03 years to accept their child's disability followed by 28% who were in the bargaining stage. Parents were mostly unaware of the government schemes and hardly availed them.

Index Terms- Multiple disability (MD), early identification, Critical age, Transdisciplinary (TD) approach, government schemes.

I. INTRODUCTION

Persons with multiple disability (PWMD) in India, which occupies one sixth of the world's population (Census, 2011) have attracted some attention with the emergence of National Trust Act in 1995 followed by establishment of the National Institute of Empowerment of Persons with Multiple Disabilities (NIEPMD) by the Ministry of Social Justice and Empowerment in year 2005 to exclusively cater to the needs of the population with Multiple Disability. Any successful intervention has to be need based and from the beneficiaries perspective. This puts forth the need to discover areas to be targeted for empowerment in this population.

According to the survey conducted by the NSSO in 2002 estimates a total of 1.8% population of the country suffers from one or the other disability out of which 10.63% (2,328,000) have multiple disabilities. This number is larger than the whole population of few countries like Macedonia and Qatar (United States census bureau, 2011). Failing to address the needs of this population leads to loss of major human resource that can contribute to the society along with emotional social and personal conflicts at the individual level and at family level.

In India two major acts define the PWMD. Person with disability act (1995) class 1 section 2 and the national trust act (1999), class H section 2 define Multiple disability (MD) as a combination of two or more disabilities. MD has also been defined as persons having concomitant impairments (such as

intellectual disabilities with blindness, intellectual disability with orthopaedic impairment, etc) , the combination of which causes such severe educational needs that they cannot be accommodated in a special education program solely for one of the impairments; term does not include deaf blindness (Hunt and Marshall, 2006). There is little indigenous research in the area of multiple disabilities much of this is due to lack of resources and the lack of focused professionals working in this domain.

Unlike many developed countries like United States where newborn and school screening programmes are regularly implemented by the government (Boyle & Boulet, 1997, 2005) the rehabilitation of a child or adult with disability in India is predominantly a personal affair as it is taken up by the parents the initiation of which often crosses the critical age of the child (Rout & Singh, 2010). The age and intensity with which the process of rehabilitation is initiated and continued depends a lot on the perception of the care givers. The perception of the caregivers is shaped by views of the family and society around them and the recommendations by the professionals they approach. Discovering the perception of the caregivers would help designing a need based protocol and speed up the process of rehabilitation by targeting the weak links. Further endeavours to understand parental perceptions about the service delivery system and the condition of the child would help appreciating the strengths and limitation of the person and the present service delivery system, the domains which need to be targeted, modified or emphasised during the therapy, counselling as well as in policy making and social inclusion of the PWMD at large. The aim of the present study is to discover answers pertaining to understanding the complaint of child, age of identification, different professionals approached, and issues pertaining to perception of child's problem by others, concerns of mothers and model of therapy which the parents preferred.

II. METHOD

Participants:-

A total of 40 parents consented to participate in the study from the 290 clients with MD who availed services at NIEPMD between June 2012 to November 2012. Among the parents 38 were mothers and two were fathers who regularly accompanied their children for therapy, with mean age of 39.1 years. The children taken for the study had a mean age of 9.9 (SD: ± 4.7) years. Majority of parents interviewed had monthly income of less than 65002/ month, belonged to lower middle class and lower socio economic strata and lived in nuclear families in and around Chennai.

Tool :-

A 36 item validated open-ended questionnaire designed for the caregivers was used in the study. The English and translated Tamil questionnaire was judged for its face validity by two psychologists, followed by two speech language pathologists and a special educator. The questionnaire was administered in Tamil which was the native language of the participants (appendix1).

Procedure:-

Before the interview the participant was elaborated about the aim and purpose of the study. Consent was obtained from participants and as they consented an interview was conducted in one to one setup. The responses were transcribed by one of the authors as the interview proceeded following which it was discussed and coded within two hours. The questions were paraphrased if clients did not understand the content. The data was then analyzed using SPSS version 16.

III. RESULTS

Majority of clients were provisionally diagnosed of mental retardation with cerebral palsy (MR+CP) (21/40) followed by autism spectrum disorder (ASD) with mental retardation (12/40). Other less common conditions were attention deficit hyperactivity disorder with mental retardation (ADHD+MR) and developmental delay. Age at which mothers first suspected that their child has some problem was 24.2 (SD:±24.2) months. The

conditions which aroused suspicion of abnormality in the child were primarily delayed developmental milestones (18/40), post natal risk indicators or medical condition (9/40) like epilepsy and birth asphyxia and behavioural problems seen in the child(7/40). The mean age at which mothers first took their child to a doctor for consultation after suspicion was 27.2 (SD:± 20.0) months. Majority of the clients (26/40) consulted paediatrician followed by psychiatrist (6/40) and neurologists (5/40). Other parents consulted general physician. As many as 14 children were treated with drugs alone and did not have any direct recommendations pertaining to accessing consultation from rehabilitation professional. Some doctors (7/40) advised to wait and watch as the child had developmental delay and could recover with medicines and age. Only 13(32%) doctors directly recommended rehabilitation services along with medical treatment. Referral to a psychologist for IQ evaluation and admission in play school was also recommended to six of the parents. Out of 40 parents 23 of them went for a second consultation at the mean age of 33.5 months (SD: ±30.2). Majority (18/ 23) of mothers consulted a different paediatrician rest three consulted a psychiatrist. This time 18/23 doctors advised for specific rehabilitation services according to child's needs along with medical treatment and the rest recommended to continue with drugs. The mean age of major milestones in the process of habilitation has been depicted in figure 1

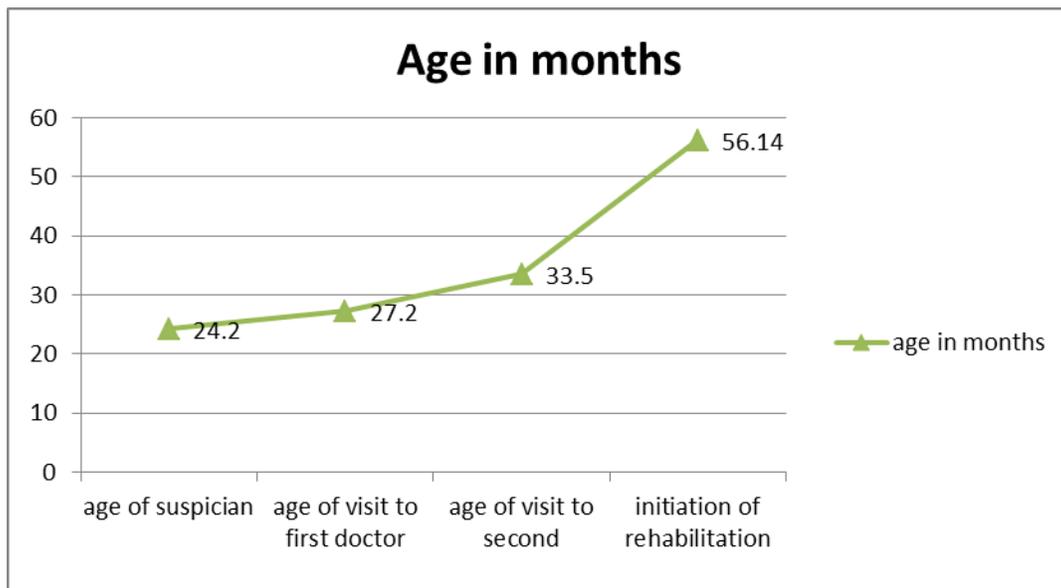


Figure 1: Mean age of major milestones in the process of habilitation

Mean age at which rehabilitation started for the clients was 56.14 months (SD:± 30.1). When the rehabilitation first started 27/40 children were non verbal and 10 had delayed speech and language. However, rehabilitation that was first recommended and initiated for the child was physiotherapy and occupational therapy (22/40). Only 15 parents gave importance to speech therapy at the beginning itself along with other therapeutic interventions. Parents were also questioned regarding their major concerns for their child at the time of interview. Adequate speech and language development was solely the main concern for parents of these children (12/40) followed by motor development

and behaviour along with speech and language delay (18/40) (figure 2). Few other less mentioned concerns were inability to carry on Activities of daily living and reading and writing (10/40). Out of 40 children 37 on evaluation had language and speech difficulties and at least 65% of them needed AAC in spite of that 17% parent who we interviewed found no major communication difficulties in their child. Parents were explained the stages of normal grief by Elizabeth Ross (1969) and were asked to indicate the stage in which they would put themselves. Most of the mothers had already accepted their child's disability (22/40) followed by bargaining (11/40) and very few mother

were still at the stage of grief and denial (7/40). Society and family's attitude was also probed into and majority of parents (27/40) reported that attitude and behaviour of family members and society mainly neighbours towards the child and parents (especially mothers) was difficult for them to manage and added on to their stress. Parents were also interviewed regarding the awareness of laws given by government for children with disability. About 28 clients were availing the free travel pass and 10002 per month allowance given by government of Tamil Nadu but rest were not aware of basic benefits.

Only 29 client's were asked questions pertaining to different work approaches as they were regular clients attending therapy in a multidisciplinary set up for a mean period of 2.18 years. Twenty of the mothers said that they will prefer Trans Disciplinary approach and seven said maybe but they were not sure, two mothers said they want to continue with the same multidisciplinary approach that they have been attending till now. Many reasons were given by the mothers as to why they prefer TD approach which were analyzed. The most common reasons given by the mothers (20/29) supporting their preference towards TD approach is that they don't need to shift the child from one room to another, would have reduced dependency on others and uniformity. Among the mothers who supported TD approach another good reason given by them was child will be better benefitted by one teacher and continuous and uniform training.

As many as 18 mothers voluntarily reported relaxed and feeling comforted after the interview. They reported to be happy by the fact that somebody wants to listen to them and their opinion matters and thanked the interviewer.

IV. DISCUSSION

The clients in the study are representative of the proportion of distributions of the clients with MD attending NIEPMD, who were diagnosed as CP+MR (48%) followed by ASD+MR (15%) (Annual report of NIEPMD, 2011-2012).

Most children develop their first words between 12 and 15 months, and it is common practice to wait until a child is 18 to 24 months and still not talking to refer the child for an evaluation (Wetherby & Prizant, 2001). The review coincide with our study where mean age of suspicion of a problem by parents is 24.83 months with a large SD of ± 25.2 months indicating the wide variance in age of suspicion by parents. The difference is probably due to nature of medical problems in children with multiple disability. Some postnatal/medical conditions like epilepsy, birth asphyxia and neonatal jaundice leading to admission or intensive medical treatment aroused immediate suspicion while others like delay in developmental milestones stir late suspicion. This is unlike the identification of single disabling condition of severe nature like hearing impairment where mean age of identification is 1.5 (SD: ± 1.04) years with a very small range of variance (Rout, & Singh 2010). Although common sense suggests that the child with MD should be identified much earlier than a child with unidisability but the findings are the other way. It is probably because of global developmental delay and visibly alarming medical conditions of the child with multiple disability (CWMD) which keeps parents engaged and anticipate less from the child. As opposed to

CWMD a child with unidisability like a child with hearing impairment specifically gets delayed in terms of language development while other domains like motor development, cognitive development etc develop normally. The delay in language alone attracts immediate attention and hence these children are identified at a lower age as compared to CWMD. Medical professionals who were mainly consulted by our clients were paediatricians (65%) followed by psychiatrists (15%) and neurologists (12.5%). In case of unidisability a doctor specializing in the specific organ is consulted by the parents; for example ENT specialist is consulted for hearing loss (Rout and Singh, 2010), ophthalmologist for visual impairment and child psychiatrist for persons with mental retardation (American academy of child and adolescent psychiatry, 2006). A considerable number of doctors approximately 53% (14+7) did not give direct recommendations to consult a rehab professional which indicates probable lack of knowledge about the restricted critical age or the work domain of rehabilitation professionals. With the betterment in health care system the number of children who would not have survived after birth is saved is increasing. A part of them tend to have lasting disability which cannot be cured (AIHW, 2009) and hence the course content about rehabilitation and disability needs to be proportionately increased especially for paediatrician, neurologist & psychiatrists. Even though the ENT refrains from recommending an audiologist for diagnosis and treatment in the first visit, it is as less as 21% (Rout & Singh, 2010) as compared to 53% in case of CWMD primarily consulting paediatrician, neurologist and psychiatrist. It is also to do with medical condition of the child. Many a time's doctors and parents wait for the child to recover in terms of physical condition and vitals following which they plan to begin rehabilitation services. However, passive stretching, sensory stimulation and speech and language stimulation do not require aggressive motor movements by the child and can be carried out by parents in consultation with the rehabilitation professional. Further consideration with rehab professionals would help getting advice about better positioning, movement and communication strategies which intern has more palliative and bonding effect and trigger the process of healing and development. To begin a focused training program the name and addresses of doctors and medical professionals visited by the parents most commonly need to be collected as done during this study and the group has to be addressed first.

On the second visit more number of parents almost 78% was advised to visit specific rehabilitation professionals. This is less to do with awareness about a rehabilitation professional and more to do with the requirement for referral and realization that medicines alone will not improve child's condition. This delay in referral leads to a loss of critical age of development which is a major phenomenon in brain and behavioural development (Michel & Mark, 2008). There are many studies that support the theory of critical age and concept of early identification and intervention. The period from 25 weeks of gestation to 5-6 months of age is most critical to development of the auditory pathway and intrun of speech and language development (Graven & Browne, 2008). A pamphlet which indicates significance of critical age and need of early rehabilitation, which is found to be convincing to doctors and trigger referrals, is enclosed in appendix II. A study done by Yashinaga and Itano in

1998 on language skills of early and late identified children with hearing loss stated that children identified before 6 months of age had better language skills than ones identified after 6 months. Based upon developmental and clinical findings, JCIH 2007 recommends speech language therapy to start as early as 6 months of age beyond which there is high chance that irreversible neurological changes can occur in the auditory pathways and cortex restricting the child's capability to grasp language (Rout & Khanna, 2012). In spite of this, early initiation

of speech therapy is not given due importance as other rehabilitation services like physiotherapy and occupational therapy which is evident by the lack of concern.

On clinical evaluation all the participants had restricted language skills but 80% of parents felt the child to be having a restricted language needing therapy. Further only 37% of them gave priority to attend speech therapy (Figure 2). This suggests the low priority placed upon communication skills for children at that age as compared to development of ambulatory skills

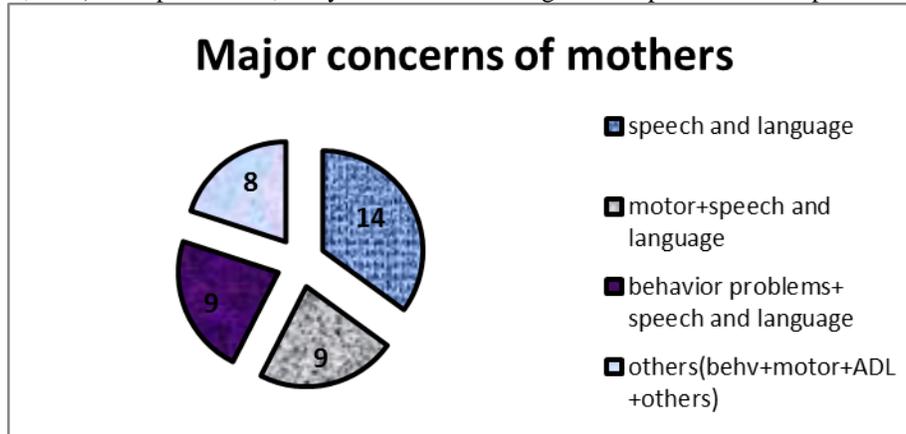


Figure 2:- Major concerns of parents of children with multiple disability

Family accounts of families' experiences frequently contain examples of unsympathetic and unhelpful interventions from professionals, which may add further to family stress (Karthikeyan & Dhanesh, 2013). Parent's attitude and outlook towards their child with disability is an important factor in getting their support and contribution as co-therapist during rehabilitation. Any form of therapy especially speech therapy and occupational therapy have to be carried over to the home settings. For this parents need to be educated as co-therapists (Conklin, 1996). Especially for speech and occupational therapy the activities of daily living (ADL) are modified so as to stimulate the targeted communication interaction and motor movements. The activities have to be modified according to home situations and have to be carried out by mother or caregiver. Without accepting and understanding the child's condition it would be very difficult for the mother to carry out the activities in a play way method. To understand the parents readiness to actively participate as a co-therapist, parents were asked to rate their level of acceptance of their child with disability. Stages of normal grief given by Elisabeth Kubler-Ross in her 1969 in her book on "death and dying" was taken as the baseline and parents level of acceptance was rated according to these 5 stages i.e. denial, grief, anger, bargaining and acceptance. Among our clients 56% of mothers had already accepted their child i.e. have learnt to live with the disability and were ready for whatever comes their way. Among other parents 28% were bargaining with their level of grief and child's disability. In this stage parents will be attempting to bargain with which ever god they believe in an attempt to postpone the inevitable, this is a weaker line of defence to protect them from the painful reality. The rest 16% of parents were still at the first stage of grief. To reach the level of bargaining an average of 2.7(SD: ±1.5) years and to reach level of acceptance a mean period of 8.03(SD: ±4.2) years was taken by the parents to accept

the child's condition. To carry over the activities mother needs to completely accept her child's condition.

Lags in Communication development is the key indicator of any developmental disorder (Wetherby, 2001) and the same was seen in the participants. In a place with preponderance of children with multiple disability and developmental disabilities the proportion of speech therapists needs to be on a higher side to cater to the communication therapy needs with in a very short critical period.

Government since a long time has been giving benefits and concessions for persons with disability. In this study parents were also asked regarding the government laws they are availing and are aware off. Surprisingly only 28(70%) clients were aware of only one law i.e. allowance of 1000Rs/month and free travelling pass for government transport and the rest 12(30%) were not even aware of these. A similar finding about unawareness of government benefits was published by Sarkar & Rout in 2012. They stated that people attending a camp to access disability certificate were unaware about the benefits which could be availed by the help of the disability certificate. Many awareness camps needs to be arranged by institutions and NGOs with the purpose to educate public regarding the benefits given by government for persons with disability and the procedure to avail these so that they can improve their quality of life. Mass media and television can also be helpful in spreading alertness regarding the same. Parents are mostly unaware of the government schemes and hardly availed them. After being briefed about the services during the interview, many were not very excited about the facilities as they were scattered around the city and travel with the child was a major concern. Most of them agreed to the fact that after a long travel and visit to a new place the child falls sick due to the disturbed daily routine which is very difficult to handle. A few parents after being briefed about the disability certificate and its benefits made a try. Three of

them could manage to get it but were not very happy as they had to follow up many times to obtain the disability certificate and a few government benefits. They found the exercise to be physically, economical and above all emotionally taxing. One of the major reasons was due to the non inclusion of people with MD under the seven categories of disabilities as prescribed under the PWD act, 1995(Government of India,1996). It was up to the medical professional to decide whether to give a certificate or deny even if he decided to give a certificate he had to spend some professional time to think which disability the child has to be fit into. All the parents felt the need to get people with MD defined clearly under the law. The parents put forth a proposal to create a single window service centre. The single window centre as proposed by the three parents was expected to cater to 'womb to tomb' needs starting from a obstetrics and gynaecology unit to develop early intervention strategies along with facilities for check up and delivery for the population with special needs to a long term respite care centre.

About 30 Number of parents had been attending regular therapy by a multidisciplinary team, for a period of 2.18 (SD: ± 1.8) years. Parents were explained about transdisciplinary (TD) approach and asked for their preference regarding the two approaches. In TD approach professionals share information and skills across disciplines. Assessment is collaborated so that one individual may do all or most of the interaction with the child, whereas others observe or make suggestions for the interactor to use during the assessment process. Team members work together whenever possible. They train and receive training from each other in reciprocal interactions. Role release is employed (Paul, 1995). This involves sharing information and having team members help each other perform activities traditionally reserved within disciplines. Parents preferred TD approach owing to two primary reasons. Firstly, to avoid the transition from one therapist to another which placed a heavy demand to move the child, adjust with different therapists and manage time. Secondly the presence of one therapist would lead to amalgamation of all the activities during the session and a better continuity of therapy.

V. CONCLUSION

Due to lack of universal newborn screening programs in India there is a massive delay in identification and initiation of rehabilitation in CWMD.

As soon as parents suspect a problem with their child they first go to doctors (mainly paediatrician and psychiatrists) who in first visit usually don't refer the clients to rehabilitation professionals. This leads to loss of critical age of child as well as delay to develop acceptance which is core to process of rehabilitation. Specific doctors and institutions have to be targeted where majority of the population of the country consult. In absence of universal screening programs efforts to sensitize specific doctors popularly accessed for a type of disability will help speed up the process of rehabilitation by approximately 2.5years (32months).

Parental concern are mostly pertaining to motor and speech and language development for which they showed preference towards TD team approach as compared to a MD approach

which is been practised in India and so there is a need to evolve this new approach.

Even though government has quite a number of schemes for the welfare and empowerment of persons with disability hardly few parents know about the very basic transport concessions and the rest 30% don't even know this basic amenity. There is an urgent need to spread awareness about the schemes and the process of procuring these through Mass media.

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Appendix I

Interview Questions

1. Name & Age of the child:-
2. Address:
3. Provisional diagnosis:-
4. Age of mother: -
5. Literacy of mother:-
6. Family type: - Joint/nuclear
7. Income:-
8. Age at which mother first suspected a problem:-
9. Reason behind the suspicion:-
10. Reaction of the family:-
11. Age of visit to the first doctor:-
12. Profession of first doctor:-
13. Address:
14. Advice given by the first doctor:-
15. Age of visit to second doctor:-
16. Profession of second doctor:-
17. Address:
18. Advice by second doctor:-
19. Age of visit to third doctor if any:-
20. Profession of 3rd doctor:-
21. Address:
22. Advice given by 3rd doctor:-
23. Age of child when rehab started:-
24. Which rehab was first initiated:-
25. Was child speaking when rehab started:-
26. Did any professional/Non professional recommend speech therapy:-
27. Duration since attending NIEPMD:-
28. Different departments you attend:-
29. Do you feel difficulty in doing so:- yes/ no sometimes
30. Do you prefer a trans disciplinary training:- yes/no/not sure
31. If no/yes why:
32. What are your main concerns for your child at this point of time:-
33. What is different or 'abnormal' in your life because you have a special child:- (0 to 5)
34. Stage of Adjustment: Grief, denial, anger, bargaining, acceptance.
35. Do you know of some laws for the disabled?

Appendix II

We are Late !! Pl refer for Speech and Hearing evaluation

However **Early** is **LATE**. Core **CRITICAL AGE** for Speech 20 weeks gestation to 6 months age



15 weeks of GA: Cochlea is Anatomically ready
20 weeks GA: Cochlea Functionally ready.
(Hall, 2000; Pujol and Lavigne-Rebillard, 1992).

28 to 29 weeks GA: Rapid tonotopicity/tuning /neural connections of hair cells. Low freq first followed by high freq. (Graven & Browne, 2008).

In utero learning of sounds, voice, and music has been demonstrated at as early as **32 weeks' GA** (Moon & Fifer, 2000)



25 weeks Gestation to 6 months: Its most critical to the development of the neurosensory part of the auditory system.
(Graven and Browne, 2008)



The density of the neurons increase till 2-3 years of age followed by selective neural pruning, at the age of five reducing the synaptic density in adults by 50 – 100%
(Chechik, Meilijson and Ruppin, 1997)



Brain operates on “use it or lose it” principle
(Carnegie Task Force on Meeting the Needs of Young Children, 1994; Ounce prevention Fund, 1996). JCIH, 2000, 2007 recommends assesment by 1 month, identfn by 3 mo and therapy by 6 months.

